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ABSTRACT

Survey responses of 46 state directors of special education regarding the problems faced by severely handicapped students who exit public schools but require adult services indicated that severe discrepancies exist in most states between the number of people needing adult services and the capacity of such service systems to meet these needs. Two-thirds of the respondents felt that public school leavers have more difficulty accessing community adult services than do individuals leaving state institutions or those who are under the care of state agencies. Two-thirds of the respondents also indicated that confusion exists regarding which state agency and/or adult service provider should receive student referrals. Approximately 70 percent of the respondents indicated that parents are becoming increasingly aware that adult service providers do not operate under a serve-all mandate similar to public education; as a result, increased lobbying is occurring or beginning to occur in most states. Over 60 percent of the respondents indicated that greater emphasis should be placed on recreational and leisure services as an integral component of community life for handicapped adults. State directors of special education believed that additional cooperative planning is necessary to build the continuum of adult services needed to maximize participation of severely handicapped individuals in the community. (CB)

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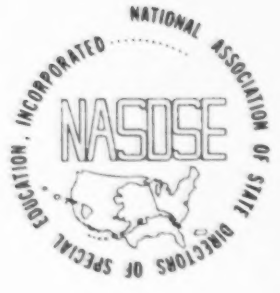
Severely Handicapped Youth Exiting Public Education:

Issues and Concerns



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Severely Handicapped Youth Exiting Public Education: Issues and Concerns

Foreword

One of the most frequently asked questions in special education today is: "What will happen to handicapped students when they are no longer eligible for public education?"

There is a growing realization among parents, advocates, and educators that the only service mandate for handicapped individuals is in public education. As students approach the age of 21, parents and professionals seek out other human service agencies in an attempt to enroll students who are still in need of assistance in community programs which will provide the continued services and/or employment preparation they require. Unfortunately, in the absence of a coordinated adult human service program, many handicapped youth must stay at home and/or be placed on long waiting lists for the limited services available.

During the 1983 reauthorization of the Education of the Handicapped Act (EHA), the federal government reflected on the achievements made by handicapped students with the help provided by EHA. While the achievements had been noteworthy, the reauthorization highlighted the need for continued services beyond school age and focused on the need to identify the size and scope of the problem.

The reauthorized EHA required the education service system to collect data on the number of handicapped youth exiting the system and their anticipated service needs. The subsequent reauthorization of the Developmental Disabilities Act and the Rehabilitation Act required state agencies governed by these laws to incorporate into their state plans exiting data collected by the State Education Agency (SEA).

Through reauthorization of existing legislation, Congress attempted to establish a coordinated bridge in services between the public schools and community adult services for handicapped persons. Communities and the many agencies serving handicapped adults are grappling with the multiple problems associated with establishing a coordinated system for community services. This is proving to be a complex, expensive task requiring coordination between state and local governments and, in most instances, the reallocation of existing resources and/or the generation of new tax revenues.

In an attempt to obtain information on the current ability of this evolving community-based adult service system to serve the needs of handicapped students exiting the public schools, state directors of special education were surveyed. The survey instrument was developed by the National Association of State Directors of Special Education (NASDSE) and personnel from the U.S. Department of Education, Special Education Programs. This paper reports the results of that survey and suggests several implications of the survey findings for service delivery to the adult handicapped population. The authors are William Halloran, Susan Engelke, Agnesanne Donehey, Linda Lewis, and Sharon Walsh.

Background

Recognition of two major nationwide developments is critical to understanding the need for data on students exiting the educational system. These two trends, whose origins can be found many years earlier but which emerged with strength in the 1960's and 70's, are:

(a) deinstitutionalization and resultant community integration of severely handicapped persons, and

(b) federal and state education laws which affirmed the right of all handicapped children to a free, appropriate public education.

The combined effect of these trends has resulted in more severely and multiply handicapped students being served by the nation's public schools in the last decade than ever before. How these two developments have affected the population of handicapped students served in local communities by our public schools is discussed below.

Deinstitutionalization and Community Integration

The impetus for the deinstitutionalization trend derives its strength from the litigation and court decisions occurring during the 1970's (Braddock, 1981; Laski, 1985; Willer, Scheerenberger, Intaglia, 1978). Laski (1985) contends that this legal foundation of the handicapped person's right to habilitation has common origins with endeavors to provide access to free and appropriate education. Advocacy groups in the early right-to-education case (Pennsylvania Association for Retarded Citizens [PARC] v. Commonwealth, 1971) pressed for legal action against school exclusion and not for closure of institutions (Laski, 1985). Consequently, institutions could no longer serve as substitutes to public education (President's Report to Congress, 1977).

Subsequent research supports the success of these actions. Institutional populations have decreased by 18% between the years 1970 and 1976 (Willer, Scheerenberger, and Intaglia, 1978). A recent nationwide census estimates that institution populations will continue to decline and will fall under 100,000 by the mid-1980's (Braddock, 1981). Scheerenberger's (1982) survey of public residential facilities indicated a decline of new admissions across all levels of mental retardation and reported a 13 percent increase in the percentage of residents 22 years of age and older since fiscal year 1975-76. Lakin et al. (1983) corroborate this finding stating that by the mid-1970's, a substantial change was shown in the mean and median age of a person's first admission to residential care.

This population shift and increasing age for first admissions suggest that public school systems are rendering services to severely disabled children that at one time were provided by state institutions (Reiss and Trenn, 1984). As the process of deinstitutionalization continues, care providers can expect an increasing number of referrals of the more severely impaired from the public schools. Results from an investigation of service agencies in New York State alone indicate an increase of clientele described as being multiply and severely handicapped, as compared to client characteristics prior to 1972 (Intaglia, Kraus, Willer, 1980).

Education Laws and the Schools' Response

While federal and state laws guaranteeing handicapped students the right to a free, appropriate public education have resulted directly in an increase in the number of disabled children being served by our nation's public schools, they have also led to qualitative improvements in the education of these children. In many public school settings, handicapped persons are showing dramatic achievements in academic and vocational education. The U.S. Department of Education reported findings in 1985 that increased capabilities and the decreasing need for services by some can be directly attributed to emphasis on early identification and intervention. These gains have raised expectations and have resulted in changes in curricular content and focus.

Momentum is increasing to integrate students into the mainstream of our society. According to Brown et al. (1976), successful integration depends on curriculum content defined by the "criterion of ultimate functioning." Contemporary curriculum content is now characterized by its emphasis on interpersonal interactions (Certo and Kohl, 1984), and the acquisition of employment skills (Ford, Brown, et al. 1984; and Hill, Wehman, Horst, 1981). The societal demands associated with integration necessitate a comprehensive and future-oriented educational program.

This future orientation towards adult life in the community implies that a continuum of community services should be available to maintain a handicapped person's maximum level of independence, productivity, and community participation (Wilcox and Bellamy, 1982). Educational advancements by handicapped students accentuate the growing discrepancy between existing adult service models and the increased capacity of school leavers (McDonnell et al. 1985, Boles and Bellamy, 1985).

This discrepancy has two aspects. First, the handicapped individual who has gone through the services of the schools requires a different type of post-school ser-

vice than was provided 20 years ago. These handicapped individuals are better educated, better trained, and have higher aspirations. Equally important, their families have higher aspirations for them. Second, there are individuals who need access to community-based resources who historically were expected to need only custodial community resources.

Both of these types of requirements are changing the demands being placed upon adult service systems. The heterogeneity of persons leaving schools and institutions requires a complex array of services, not just a single service such as an institutional home for life. Unfortunately, community adult service systems are having difficulty keeping pace with the variety of needs and number of persons who are coming to them.

Results from a 1985 survey of state administrators of educational agencies, vocational rehabilitation, and community residential programs (McDonnell et al., 1985), indicated 91 percent of state vocational rehabilitation personnel and 97 percent of those respondents representing community residential programs reported substantial waiting lists for services. Projections indicate a continued increase of this phenomenon with no resolution to the crisis on the horizon. This serious shortage of vocational and habilitative services for handicapped adults could lead to increases in reinstitutionalization. (McDonnell, et al., 1985).

Description of the Survey

The purpose of the survey was to obtain information from state directors of special education regarding the problems being faced by severely handicapped students exiting the schools who require adult services. The survey consisted of two parts (see Appendix A). The first was used to ascertain the degree to which state directors of special education view the well-documented lack of coordinated adult community services to be a problem for severely handicapped students exiting public school sponsored programs in their state.

The second part was designed to obtain state directors' perceptions regarding the ability of community-based adult service programs to provide a continuum of services for handicapped adults at this time. For this part of the survey, respondents were asked to agree or disagree with a set of statements describing reported problem areas in transitioning severely handicapped students from public schools into community services.

For the purpose of this study, the following operational definition of *student* was used:

> *Individuals who would be considered to have a poor prognosis for living and/or working independently when they leave school and could benefit from community-based living and day programming including supported work.*

The survey was transmitted in August, 1985 to all 50 state education agencies via SpecialNet, NASDSE's computer-based communication network, and responses were sent back to the NASDSE mailbox. Initial responses were received from 33 SEAs; additional responses were submitted after followup telephone calls. Responses were received from a total of 46 state directors of special education or their designees.

Survey Results

The responses of state directors of special education confirmed that the more severely handicapped students aging out of public school programs face significant problems in finding and accessing appropriate adult services to meet their continuing needs for assistance. Among the problems identified were:

- the limited availability of community-based services,
- competition with other clients for available programs,
- the lack of effective coordination between schools and the adult service agencies and within the adult service community,
- parental concern over the situation they and their children encounter in the transition from the school to adult services,
- the need to address the importance of leisure and community life arrangements in transition planning,
- lack of state legislation to expand community-based services.

Availability of Community-Based Adult Services

Over 80 percent of the respondents indicated that a severe discrepancy exists in their states between the number of people needing adult day training, treatment, or supported work programs and the capacity of adult service systems to meet the needs of exiting students. States rated the problem on a five-point scale ranging from minimal (1) to severe (5). The result was an average of 4+, indicating that state directors of special education agree that a serious problem exists. For severely handicapped students, transition from school to adult services

appears to be an exception rather than a common practice. The vast majority of state directors agreed that in their states waiting lists of a year or more leave the individuals "on hold" for many community services.

Public School Leavers Appear to Be Second Priority for Community Services

According to 67 percent of respondents, public school leavers have more difficulty accessing community adult services than individuals leaving state institutions and/or those who are under the care and custody of state agencies. On a five-point scale this was also rated as a significant problem, approaching 4 on the scale. Approximately 90 percent of the respondents indicated that agencies serving handicapped adults do not utilize public school enrollment and exiting data adequately when projecting adult service needs. In the past, the lack of statewide data on the number and needs of students exiting special education has undoubtedly hampered the ability of adult service agencies to anticipate and plan for the provision of services for handicapped young adults. But the recently implemented EHA requirements that state education agencies collect and report such data should measurably improve the planning ability of state and locally based adult service programs.

Greater Interagency Coordination Needed

Sixty-seven percent of respondents indicated that confusion exists regarding which state agency and/or adult service provider should receive referrals on students "aging out" or exiting public schools. They indicated that interaction between state agencies administering adult service programs and SEAs must be improved if the continuum of services for adults is to become a reality. Respondents were unanimous in their assertion that local school districts have neither the resources nor the capacity to provide followup services or support to school leavers over a period of years after they exit public education.

Increasing Parent Awareness

Approximately 70 percent of the respondents indicated that parents are becoming increasingly aware that adult service providers do not operate under a serve-all mandate similar to public education. In contrast to education's zero-reject model—that is, public schools are responsible for serving all handicapped children—adult service agencies currently provide specific types of services permitted by their authorizing legislation to certain groups of clients and only within the limits of available funds. State directors indicated that increased lobbying for adult services is occurring or beginning to occur in most states.

Greater Emphasis Needed on Leisure and Other Aspects of Community Life

Over 60 percent of the respondents indicated that greater emphasis needs to be placed on recreational and leisure services as an integral component of community life for handicapped adults. They indicated that community living arrangements, outside the individual family residence, are seldom made for individuals "aging out" or exiting public schools. They appear to be concerned that certain aspects of community life should be receiving greater emphasis in transitional planning.

State Legislation Moving Slowly

Only a few respondents indicated that there have been recent legislative or appropriation actions in their states designed to expand community-based services for students exiting the public schools or for the broader adult handicapped population. A review of transition and adult services legislation recently enacted by a few of the states confirms that while progress is slow and the mandates sometimes limited in their scope, some states are making attempts to remedy problems adult handicapped individuals face in accessing appropriate services.

Implications

Successful transition can occur only when there are continuing services available for those who need them. Cooperative programs in special education, vocational education, and vocational rehabilitation over the past years have enabled many mildly and moderately handicapped individuals to become well-adjusted, suitably employed members of our communities. However, the results of this survey indicate that state directors of special education believe a significant problem exists regarding the transition of the more severely handicapped students exiting public schools to programs and services necessary for them to function in our communities.

Availability of Community-Based Services

State directors indicated that community-based services for severely handicapped adults are very scarce. It appears that without significant expansion of the capacity and nature of adult service programs, the more severely handicapped students exiting the schools will not be able to access continued programs and services.

Almost two-thirds of the respondents reported that public school leavers have more difficulty accessing community adult services than handicapped individuals from state institutions and/or those under the care and custody of state agencies. Public Law 94-142 allowed the more severely handicapped the benefit of public education. Ironically, these individuals, who otherwise would probably have been the responsibility of the state agencies, appear to be second priority for adult services in the communities in which they reside and attend public schools.

Most special educators applaud the recognition of the courts in ordering changes through the process of deinstitutionalization. The unintended consequence, however, is that the court orders have sometimes created a "protected class," thereby consuming the scarce resources that are available. The effect is that there are only limited resources left for individuals who have been in the public school stream, rather than the institutionalized stream. Service dollars are exhausted by these court orders.

More positively, the court orders establish a precedent for adult services. These orders often define services that must be made available to deinstitutionalized populations. The level of services prescribed for this population becomes a standard. This standard often includes residential, recreational, medical, training, and employment services that would be appropriate as well for individuals aging out of public schools. In effect, the proper future for all handicapped individuals is being charted in these orders aimed at a small segment of the population. The dilemma is that until now the resources have been largely focused on this small segment, because the money is simply inadequate.

Enhanced Interagency Coordination

In the survey described earlier, state directors of special education confirmed that confusion exists regarding which state agency and/or adult service provider should receive referrals on students "aging out" or exiting public schools. While states are being charged with the responsibility of identifying students exiting public schools and identifying their continued program and service needs, the transfer of these needs to adult service agencies has not become a formalized process. It appears that at the present time, most states have not developed a statewide planning process addressing the needs of individuals exiting public schools.

Respondents to the survey also confirm that local school districts do not have the resources or capacity to provide followup support services over a period of years to exiting students. Coordination between public schools and adult service providers must be enhanced to bring about the planning and program development necessary to build the continuum of services to respond to the needs of disabled adults in our communities.

Hopeful Signs of State Legislative Action

Recent legislation in Massachusetts, New York, Pennsylvania, and a few other states has begun to address the coordination issue. The purpose of this emerging legislation is to provide handicapped persons a clear way of moving into the state human service system immediately after leaving public schools. This new body of legislation contains the following types of requirements:

1. A single point of entry into the adult human service system, with the responsibility for management of the referral process assigned to the executive office of the state's human service program.
2. Requirement that the schools, in consultation with families, initiate referrals at least three years prior to the student's anticipated exiting date.
3. The development of individualized transition plans by schools and adult service providers, working cooperatively, at least two years prior to the anticipated exiting date.
4. Case management responsibilities with a tracking system that reports the handicapped individual's progress to the agency or office responsible at the single point of referral.

Experience has shown that enhancing coordination among agencies is a complicated process in which differing agenda and contrasting federal and/or state regulations are often obstacles to cooperative efforts. In fact, interagency cooperation is the key to successful coordinated community services. The critical nature of the challenge should lead people to focus in on the consequences of inaction on the more severely handicapped adult population emerging from the public schools.

Over the past 15 years, parents and families have been encouraged to keep their children at home with the implied promise of free and appropriate public education. As characterized widely by the popular media over the last two years, there appears to be growing realiza-

tion among parents that adult service systems do not have mandates to serve *all*, even leading some families to now question their early decisions to keep their children in public schools. This parental dilemma must be examined and appropriate efforts made to assure that the promise of public education—a more normalized, productive life for handicapped persons—does not evaporate at adulthood.

Recreation, Leisure, and Community Leaving

Emphasis on the transition from school to adult and working life is sometimes criticized for its perceived overemphasis on work. While we would not agree with the critics, we believe greater emphasis must be placed on recreation, leisure, and community living.

Public schools play an important role in preparing handicapped individuals to become well-adjusted, suitably employed members of their communities. Leisure, recreational, and independent living skill development should be an integral part of the curriculum for severely disabled students. An increasing number of states are requiring "Individualized Transition Plans" for handicapped youth. These plans should be addressing these major life functions and be taken into consideration when making post-school placements. When we work toward our task of developing a continuum of responsive adult services in our communities, recreation, leisure, and community living opportunities must be included.

Conclusion

The results of the survey indicate that state directors of special education believe that severely handicapped students face significant problems in finding adequate and appropriate adult services to meet their needs within the community. Without intervention, this severely handicapped population aging out of our public schools over the next several years will continue to experience extreme difficulty accessing community-based adult services responsive to their needs. Additional cooperative planning is necessary to build the continuum of adult services needed for many handicapped individuals to maximize their participation in our communities.

Deinstitutionalization and the mandate for free appropriate public education have led to an implied promise of responsive adult services within our communities. Under current laws and funding levels this promise is not being met, at least not for *all* handicapped adults. The creation of a responsive continuum of adult services does not fall on any one adult service providing agency. Rather, it requires the ideas, cooperation, and commitment of all service providers, advocates, parents, and community leaders to make good on the promise of adult service and address the problem of creating a responsive continuum of service. In the past, combined advocacy of this nature led to the passage and funding of P.L. 94-142. Such a coordinated approach could again be successful in meeting the needs of handicapped individuals by making a coordinated adult services continuum a reality.

Appendix A

Survey Questionnaire

The purpose of this quick response survey is to obtain information on the more severely handicapped students who are "aging out" or exiting public school programs and seeking continued programs and services in community-based adult programs.

Operational Definition of Student:

Individuals who would be considered to have a poor prognosis for living and/or working independently when they leave school and could benefit from community-based living and day programming including supported work.

Questions:

1. Do the students who leave or "age out" of public school programs have difficulty enrolling in day training and/or treatment programs for adults?
2. If your response to question #1 was yes, do you feel that a discrepancy exists between the number of people needing adult day training, treatment, or supported work programs and the capacity of adult service providers to meet the needs of existing students?
3. If a discrepancy exists (question #2), please attempt to rate the magnitude of the problem on the scale below.

   1 2 3 4 5
   (Minimal) (Severe)

4. Do the public school leavers have more difficulty accessing community adult services than individuals leaving State institutions and/or those who are under the care and custody of State agencies?
5. If you feel that the public school leavers are a lower priority than the State agency population, please attempt to rate the magnitude of the problem on the scale below.

   1 2 3 4 5
   (Minimal) (Severe)

Please identify by letter the statements which might pertain to the adult services issue in your State.

a. Waiting list for community adult services make it difficult for individuals leaving public schools to transition into adult services.
b. Students leaving public school programs would be added to existing waiting lists and would have to wait at least a year before accessing services.
c. Parents are becoming more aware of the fact that adult service providers do not operate under a "zero-reject" mandate similar to public education. Therefore, increased lobbying for adult services is occurring or beginning to occur.
d. Recent State legislation and/or State appropriation have attempted to expand community based services for school leavers and/or the adult handicapped population.
e. Concern has been expressed that public school leavers have less chance of accessing services than individuals in State institutions or under the care and custody of State agencies.
f. State agencies and other adult service providers do not adequately utilize enrollment data and/or exiting data obtained from the public schools when projecting adult service needs.
g. Confusion exists regarding which State agency and/or adult service providers should receive referrals on students "aging out" or exiting public schools.
h. Local school districts do not have the resources or capacity to follow up school leavers over a period of years.
i. Community living arrangements, outside the individual's family residence, are seldom made for individuals "aging out" or exiting public schools.
j. Interaction between State agencies administering adult service programs and SEA's will have to be improved if the continuum of services for adults is to become a reality.
k. Greater emphasis must be placed on recreational and leisure services as an integral component of community life for handicapped adults.

Appendix B

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